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ABSTRACT

This paper reviews the literature and offers an international perspective on current programs and issues in training individuals with mental retardation to parent, nurture, and care for their children. The first section reviews the limited research on the development of children of mothers with mental retardation, some existing parent training programs, and outcomes in parenting education for these parents. The second section specifically addresses parenting and sexuality education for parents with mental retardation. Some guidelines for parents are offered. A section on international perspectives describes a Canadian parenting education program for this population. Parenting education efforts in Australia, Pakistan, Finland, and Korea are briefly reviewed. The procedure used in Hong Kong to assess an individual's ability to understand and consent to the responsibilities of marriage is explained. The paper urges more systematic and standardized research in this area. (Contains 38 references.) (DB)

Teaching the Mentally Retarded Parenting Skills: International Perspectives

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Running head : teaching

Abstract

As normalization continues to permeate contemporary society, services to mentally retarded individuals continue to expand. This paper discusses the current "state of the art" of training mentally retarded individuals to parent, nurture, and care for their children. Contemporary programs will be reviewed and an international perspective offered.

With the advent of deinstitutionalization and "mainstreaming" more and more mentally retarded individuals are being served in the community rather than in large psychiatric facilities or developmental centers. Services to these individuals has expanded and become more relevant to their needs. One area of need has been the social and interpersonal realm. Mentally retarded individuals have needs for social stimulation as well as sexual and emotional needs that must be addressed. Many individuals want as normal a lifestyle as possible and that may include, in certain instances, marriage and a family. With marriage comes the possibility of offspring and it is incumbent upon our society to provide the skills needed for these mentally retarded individuals to adequately parent their children. The children may or may not be mentally retarded, or one of the married couple may not be mentally retarded. Or, one of the couple may have adaptive behavior deficits, but not cognitive deficits or vice versa. Thus, program planning must include a high degree of individualization.

There is little in the literature regarding the efficacy of programs regarding the teaching of parenting skills to mentally retarded parents. There is also little regarding long term follow up and evaluation of the efficacy of said programs. Further, there is little regarding what specific skills should be taught to parents regarding the rearing of their children. Indeed, even average and normal parents

have different concerns as their children grow from infants to children to adolescents and young adults.

Bornstein (1995) has recently edited a multi-volume text on parenting and delineated various aspects of parenting different type of children at different stages in the life cycle (infants, gifted, adolescents, aggressive, Down Syndrome, twins, etc)

We will attempt to review the existing literature, discuss international perspectives and philosophies and delineate future research agendas. It is recognized that it is difficult to procure primary sources, even with the Internet and modern technology.

Feldman, Case, Towns and Betel (1985) conducted an early exploratory study in Toronto, wherein they examined the development of 12 two year old children who had been reared by mentally retarded mothers. They did find evidence of language delays, but also found that in cases where a mother had previously lost custody of a child, there was also slow development. This study examined children of mentally retarded parents at 2 years of age and did not include any long term follow up.

Budd and Greenspan (1985) explored the parameters of successful and unsuccessful interventions with mothers seen to be mentally retarded.

They concluded that parent training programs had to be lenthier, more intricate, more elaborate, more directive and

of longer duration than for nonhandicapped parents. Limited generalization was also a concern.

Fantuzzo, Wray, Hall, Goins, and Azar (1986) investigated the training of mentally retarded mothers who had been identified as "maltreaters". Using the work of Foxx and his colleagues (Foxx and McMorrow, 1985, Foxx McMorrow and Mennemeier, 1984, Foxx, McMorrow, Schloss, 1983,Foxx, McMorrow, Storey & Rogers, 1984) Fantuzzo et al worked with three mothers to enhance performance, self monitoring and response specific feedback.

Seagull and Scheurer (1986) based basically on their review of the literature and their data concluded that "given the complexity of the problems, and the lack of readily available solutions...the needs of the children to be nurtured and protected, must, at least be better served. (p.500). Their research showed that of 64 children,(seen from 1 to 7 years earlier) only 11 remained with their low functioning parents and that 6 had been relinquished for adoption, nine were placed in foster care and two had died, 2 had been awarded to the non retarded parent and for 34 courts had terminated parental rights.

Heighway, KIdd-Webster and Snodgrass (1988) described the Positive Parenting Project (PPP) and delineated many of the problems in terms of working with mentally retarded parents. Often, they are unable to access the human services system, they have difficulty coping with life themselves,

have difficulty learning parenting skills, have not made routine such basics as immunizations, physical exams and have trouble differentiating developmental difficulties from discipline problems. Anecdotal evidence was presented to indicate the improvement of parenting skills as well as the need for intensive on going follow up.

Pomerantz, Pomerantz and Colca (1990) discussed a Specialized Family Program for deinstitutionalized disabled individuals. Recongizing the 1977 Proceedings of the WHite House Conference on the Handicapped which indicates the right of persons with disabilities to marry, procreate and rear children (Proceedings, 1977), the authors attempted to provide appropriate support services for several families. One case study served to exemplify the need for permanent support structures for certain families. The case study did not end on a positive note in that the child in the family had multiple medical problems, and died in intensive care. The case study dramatically indicated the magnitude of need that some families may represent and negative outcomes if extensive supportive services are not forthcoming.

Dickerson, Eastman and Saffer (1984) produced a child care training manual for adults with mental retardation. Illustrated with 68 pictures, this manual is written at a very simple level and is employed in Canada as an aid to working with mentally retarded parents.

Muccigrosso (1991) examined a more current situation,

that of pregnant teenagers enrolled in special education classes for the retarded. She advocates sex education for the mentally handicapped as the rates are disproportionately high. Preparation for future vocational/social life is also indicated.

Bakken, Miltenberger and Schauss (1993) investigated the training of parents with mental retardation and delineated the difference between knowledge and skills. In their study, they found it imperative to assess criterion specific skills in the home. Concern was raised as to generalizability and long term effects of training. Training in the home with follow-up appears to be the most needed aspect of training.

Feldman (1994) has reviewed outcome studies relative to parenting education for parents with intellectual disabilities. He examined parenting education programs in 20 studies wherein 190 parents with intellectual disabilities served as subjects. The primary focus was behavioral. The initial training, follow up and some social validity results were noted to be encouraging. However, generalization and child outcomes data were felt to be weak. Feldman concluded his review of 20 program reviews by advocating 5 areas that require additional research to : 1) increase confidence in the effectiveness of parent training 2) how various individual, family, child and environmental variables affect initial parenting problems

and responsiveness to intervention 3) more innovative programs need to be developed and evaluated 4) compare cost effectiveness and long term impact to the child 5) need to develop and evaluate preventative and remedial interventions that focus on teaching parents supervision, positive-based child behavior management, stress/anger management, noncorporal discipline, and cognitive stimulation.

Tymchuk (1992) reviewed the literature on the issue of parenting by parents with mental retardation. Certain specific variables were examined i.e. parental knowledge and skills, health care and safety, decision making, interaction and child outcomes relative to cognitive delays and emotional delays.

There are however, some research studies that indicate concern. Seagull and Scheurer (1986) followed 64 neglected and /or abused chidren children, seen approximately 1-7 years prior and found that six children had been given up for adoption, in 34 cases, parental rights had been terminated and an additional nine were placed in foster care. The authors concude that the parents cognitive limitations seemed to prevent these mentally retarded parents from employing services to assist them in caring for their children.

Currently, involuntary sterilization of persons with disabilities is also being banned by courts and courts are upholding that parenting is a basic right of all adult

citizens (Hayman, 1990).

Mathews (1992) Espe-Sherwindt (1991); Espe-Sherwindt and Kerlin (1990) and Tymchuk, Andron & Rahbar (1988) have all indicated that people with mental retardation are capable of parenting. There are, of course concerns with an "operational definition" of adequate parenting, and even with "mental retardation". There are some individuals with deficits in cognitive skills, but not adaptive behavioral skills. Others have adaptive behavioral and social deficits, but may not lack intellectual or cognitive skills. Many have been misdiagnosed in the past.

Parenting and Sexuality Education for the Mentally Retarded

Parents are most children's primary teachers, and as such, are responsible for much of their children's education. The goals of most parents is for the positive growth and development of their children, as they understand it. Most often, this includes the critical aspect of appropriate sexuality education. When parents are proactively involved in sexuality education over the course of their child's life span, this goal is met more effectively. Mentally retarded individuals, however, may lack certain subtle nuances of understanding and ability to communicate in this intimately personal realm.

How should parents, especially mentally retarded ones talk to their children about sexuality ? Most normal parents often have urgent questions and valid concerns. These

include how to discuss sex without giving their children permission to have sex, does talking about sex give young children "ideas" and exactly when should a parent talk about sex with their children ? Adolescents have questions about sex. They wonder what exactly is the right age to have sex? One could respond with a counter question i.e. when exactly is the "right age" to be emotionally intimate ?

If parents are intent upon the positive growth and development of their children, they can do the following.

1) Parents should think of sexuality as a human characterisitc to be nurtured as any other human characterisitc; sexuality is a part of, not separate from, being human.

2) Parents should begin when children are young. Parents teach children everything else about being a person and do so throughout development. Parents offer information and opportunities to learn intentionally or through teachable moments. Parents answer questions and respond to children's reactions to what they observe in the world around them. Parents can do this regarding sexuality as well. Mentally retarded parents can do this also, but they may need additional training, education and feedback.

3) Parents typically do not instruct their children in a vaccuum. Parents offer their children moral and ethical guidance. Parents instruct children how to protect themselves and how to be safe. Any education about

sexuality would also involve this kind of support and education.

4) Parents can and should rely upon any resource that is available to them to help support teaching their children. Resources should be made available to the mentally retarded at a reading level appropriate for their needs.

5) Parents should realize their children will learn about sex, and possibly experiment, regardless of the lack of parental support. Humans do not need "permission" to do what comes naturally. The mentally retarded are no exception. However, for children to be safe and become responsible, guidance must be provided. Parents are in an ideal situation to offer this guidance, but many mentally retarded individuals may need assistance and skills in this area. (Glover, 1987)

The issue of dealing with the sexuality of those afflicted with mental retardation becomes one of safety and protection. There is nothing unusual in the teaching of sexuality to those with mental retardation. The principles of sound sexuality education for all children also applies. Knowledge and experience, however, may be limited in those with mental retardation. To the degree that instruction can be offered, it should be. A key component of sexuality education for the mentally retarded is the education of those charged with their care (when applicable). As with any parent or teacher, knowledge and understanding of that

which must be imparted is critical to helpful instruction. It should be seen as an on-going process and curriculums should be made available. Books, tapes, and high interest, low vocabulary materials are needed. On going training is needed rather than quick, time limited programs (Glover,1986)

International Perspectives

Llewellyn (1990) recently reviewed the literature regarding the process of adults with intellectual disability serving as parents a) after deinstitutionalization and b) after having been identified as needing assistance. In Australia, Llewellyn notes a great disparity in terms of the definition of "adequate parenting" and a great heterogeneity in terms of parenting experiences, supportive familial networks and socio-economic backgrounds.

Llewellyn & Brigden (1995) have explored the factors affecting service provision to parents with intellectual disabilities. Client characteristics were examined , limited resources and inter-agency involvement were seen as three key crucial factors leading to provision of mainstream support services.

In Canada, one program that bears mentioning is the Parent Education Program (PEP) of Surrey Place Centre in Toronto. PEP is a non-profit, community based facility whose purpose is to help parents with cognitive challenges to become more effective and to conduct research in the areas

of developing criteria for training programs and evaluating the effectiveness of parent training programs. In this program, referral can come from parents, advocates, child welfare workers, public health nurses and family physicians. After a referral is received, a PEP therapist visits the home several times so that an idea of a typical day can be developed. Observations are made of feedings, bathing, dressing, playing etc to determine how well these activities are being performed. Referrals are also made for older children and the problem area usually centers around behavior. The next step is for the parent and other workers to identify parenting skills which will be targeted for instruction. Checklists are used to facilitate this process. The check lists are based on a task analysis approach. Each step is scored correct or incorrect. Topics include bottle feeding, crib safety and toilet training for example.

A typical Training session schemata follows :

Step 1: PEP therapist demonstrates the task step by step.

Step 2: Parent practices the task and the PEP therapist gives feedback- sometimes a manual is given to the parent with pictures depicting each step in a task as well as a written description of what to do.

Step 3: Repeat this process until parent knows how to perform the task well.

Step 4: Observe the parent performing the task 1 time a

month over the next 12 months.

Step 5: Parent receives reward for improving performance-gift certificates are used.

The PEP Program also has an ongoing assessment program for the child to catch any developmental problems early on. The PEP therapist visits at least once a week. Visits can last from 1-2 hours. Once a month parents and children are also invited to a parent group meeting at Surrey Place Centre. At these meetings, the therapist will, in addition to dealing with parenting issues, also provide assistance on issues such as housing, leisure activities and social skills.

In Australia, Booth and Booth (1995) examined case studies from twenty families wherein the parents (one or both had a learning disability or difficulty). In many cases, children were taken from parents, there was a constant fear of surveillance and inadequate supports were noted. Smith, Bland and Grey (1993) examined the situation of handicapped parents having nonhandicapped dependants.

In Pakistan, group homes and community living arrangements are common and there are still insitutions for the mentally retarded. Little formal information is available from this country.

In Finland, there are international conferences regarding various syndromes (Pyysalo, 1996) and treatment and parenting issues are addressed. Finland is currently in

a state of transition away from institutions and physicians are taking a more active role in prenatal screening and also assisting parents by giving information and heping with support groups. Institutions still exist, but transition to group living arrangements are in progress.

In Korea, there is no proper system established, but there are parent education programs regularly scheduled in three steps. Each step lasts approximately 16 weeks and these programs include sex education. Apparently there is much familial and parental involvement in the rearing of children at the current time in Korea. Rhee, Jong-Hee is the Director of the Seoul Welfare Center for the Mentally Retarded and reports that there is continuous family involvement in such situations in terms of responsibility. She directs the therapy and education department and oversees the parent education program in 13 major cities in Korea.

In Hong Kong, Leung (1995) has written about the need for "other social welfare services" which are more unconventional. These include self help groups, (Wong, 1989) informal social networks and the reality of 1997 being a revolutionary year for Hong Kong. Further, social welfare concerns are being confronted with a deficit ridden government system and increasing migration and legal concerns.

Yau and Chang (1993) have addressed the need to assess the person's ability to consent to marriage in those with mental retardation. In general, if a mentally retarded person is going to marry, and they are known to an agency, that specific agency would do something to prepare that individual for marriage. Parenthood may be another issue. Yau and Chang (1993) indicate that the U.N. Declaration on the Rights of Mentally Retarded Persons (1971) states that the " mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings." In Hong Kong, the government has reaffirmed in the Green Paper on Rehabilitation (1992) that "disabled persons should enjoy the same basic rights as other members of the community." With regard to marriage, there is no law in Hong Kong (Marriage Ordinance, 1984) preventing a mentally retarded person from contracting a valid marriage. It is essential, nevertheless, to satify the Registrar of Marriages that both parties in the marriage are capable of understanding the meaning and responsibilities of marriage (Hoggett, 1990)

The clinical psychologists at the Social Welfare Department are sometimes asked to assess such ability. In Hong Kong, anyone can marry if they have reached the legal age of consent for marriage and understand the nature and effect of marriage. Nevertheless, like people without disabilities, if anyone with developmental disabilities would like to get married, they have to abide by the

legislation governing marriage. Yau and Chang (1993) have defined the most basic meaning and responsibilities of marriage to include the following :

a) That one will enter into a sexual relationship with the spouse.

b) That one will live together with the spouse with at least some degree of permanency.

c) That it will be a monogamous relationship and

d) That the relationship is legally binding , that is, it can only be terminated by the Court.

The clinical psychologist must endeavor to ascertain the individual's ability to understand these concepts. Sadly, there is no objective test or instrument available for these purposes. Yau and Chang have developed a set of open ended questions to ascertain how mentally retarded individuals understand the above concepts.

The questions are :

1) Why do people want to get married?
2) What constitutes a marriage ?
3) If you were to get married what would be your plans afterward ?
4) What is the difference between marriage and cohabitation?
5) Can you marry another person while already married ?

In light of the fact that there is no objective measure as yet available, the skilled clinician can rely on the mentally retarded individual's comprehension and understanding of these as at least a baseline or preliminary measure of their ability to understand their responsibilities.

Other people such as parents or professionals can and

will provide advice for people with developmental disabilities to help them exercise their rights in getting married and having children sensibly. The parents of children with developmental disabilities (especially the parents of a female child) in Hong Kong are very cautious about letting their children marry, although the parents legally may have nothing to do with their children's decision if the later have reached the legal age of consent for marriage. Yet, parent's support and concern are always of vital importance in children's marriage. If the people with developmental disabilities are known to other professionals such as psychologists, social workers, or occupational therapists, they would most likely get some help from these professionals in preparation for marriage. The preparation and training may include house keeping, contraceptions, family planning and parenting. Specific programs and authors of projects are not available.

In discussing family life and community involvement, the White Paper indicates that

> " Family life education impresses upon the public the importance of family life and how it can be sustained. The principal target groups are adolescents, young adults about to marry, parents-to-be and parents...People with a disability and their families may take advantage of family life education in the same way as anyone else (Hong Kong Government, 1995, p. 83)

Obviously, problems often arise for married people with developmental disabilities if they want to have children. Having children often puts financial and extreme emotional

strain and stress upon the couple. Again, professionals and social service organizations may provide extra help for the couple if required.

If a child of a parent with developmental disabilities is neglected or abused, like any other suspected child abuse cases, the SWD may become involved in deciding what should be done to help the child (and the family) concerned. Though the paramount concern is for the welfare of the child, every effort will be made to keep the family together. Professional help and community support services will be tapped to strengthen the parental capacity and ensure the quality of care of the child. The child may be temporarily taken away from the parents or in extreme cases, committed to the care of the Director of Social Welfare as a ward.

In India, basically non governmental organizations (NGO's) are responsible for looking after mentally retarded children and citizens. Often the various state governments in India award various grants to such institutions. Community based rehabilitation (CBR) is the programme which is currently in vogue in many parts of India.

It is very rare in India that mentally retarded individuals are allowed to marry. In some cases, if the famuily bonds are very strong, individuals are allowed to marry but the families shoulder much of the burder of rearing the children and helping the families cope.

In India, mothers assume a great deal of the burden of rearing children, often with the aid of the CBR staff. Such organizations are often termed "Sewa-in-Action" ," CADABAM" Spastoes Society of India and these organizations endeavor to assist the families and extended families in coping with these situations. Specific programs to teach parenting skills are not formally recognized or distributed.

Procuring specific information from European and Asian countries is problematic. In addition, one often feels that one is given the "official position" when the reality may be somewhat different. Procuring specific information for the teaching of parenting skills is difficult. Further, the little information available is accesible only to certain professionals.

Summary and Conclusions

This paper has attempted to review some of the existent literature regarding the teaching of parenting skills to mentally retarded parents. There is a lack of systematic research in this area, and nations vary greatly in their definition of mental retardation and how best to address these issues.

As we approach the year 2000, it may be necessary to take a more systemic view of this problem and standardize procedures internationally. The ultimate concern is for the welfare of all children, in all nations, of all parents.

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